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Health and Healthcare Seeking Behaviour among Transgender in Mumbai: Beyond the Paradigm of HIV/AIDS

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Abstract

Over the last two decades, health research on transgenders (TGs) has focused mainly on their sexual practices, leading to lack of information on their health problems and healthcare seeking behaviour beyond Sexually Transmitted Diseases (STD) and HIV/AIDS. This study aims to understand reported morbidities, treatment seeking behaviour including health expenditure among TGs in a slum in Mumbai, India. Using mixed methods (survey and in-depth interviews), in addition to background characteristics, information on morbidity, healthcare seeking behaviour, dietary patterns and substance abuse was obtained from 110 TGs. About 61 per cent TGs reported common illnesses in the last six months and about 41 per cent reported chronic illness in the last one year. Among those who reported such illness, a very few availed government health services. About 53 per cent and 61 per cent reportedly consumed alcohol and tobacco respectively at the time of interview which is way above that of the general population in India. Further, over 80 per cent of TG do not have any savings for emergency illness and only 16 per cent have some knowledge about government health insurance. Poor utilisation of government health services and lack of awareness of government health insurance impose a heavy economic burden on TGs who are already vulnerable due to the stigma around their gender identity.

Key words: Transgender, health problems, health seeking behaviour, HIV/AIDS.

I. Introduction

'Transgender' (TG) is a term used to define individuals with a gender identity that is incongruent with the gender identity accorded to them at birth (Burdge, 2007; Melendez & Pinto, 2007). TG is an umbrella term that subsumes a wide range of categories of individuals who express their gender differently from traditional gender norms, such as transvestites, transsexuals, cross dressers and also men having sex with men (MSM) (Burdge, 2007; Chakrapani et al., 2011; Horwath et al., 2014; Melendez et al., 2006; UNDP, 2012). Research on TGs however, has often missed out on these socio-cultural differences, thereby homogenising them by concentrating only on their sexual orientation.

In India too, the TG community has been categorised as non-conformants of the dual gender code using terms like 'tritiya prakriti' or third gender. There has been a historical and traditional reference to TGs as gender-variant males, commonly called 'Hijra' accorded with powers of luck and fertility as per ancient Indian myths (Kalra, 2012; Khan et al., 2009; Agoramoorthy & Hsu, 2014). Though studies have reported that there can be different constructs of gender-variant males, based on the complexity of sexual partnerships and identification with feminine or masculine characteristics, they are commonly homogenised using the term MSM (Hernandez et al., 2006). Such

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homogenisation has been the result of public health and HIV intervention programmes, which categorised MSMs/TGs as a high-risk group (Ramanathan et al., 2014; NACP, 2006)

This follows a global trend that began with the emergence of the HIV/AIDS epidemic in the 1980s, where TGs including members of the Lesbian, Gay, Bisexual and Transgender (LGBT) community were identified as a group 'at risk' due to their sexual practices (Boehmer,2002). This led to research focused heavily on Sexually Transmitted Diseases (STD) and HIV in this population of sexual minorities, overshadowing focus on their health status and treatment seeking behaviour for conditions other than HIV/AIDS (Boehmer, 2002; Melendez et al., 2006). As Such singular focus has shaped how the TG community has been represented or 'under represented' in research (Melendez et al., 2006.). Hence, understanding health status and treatment seeking behaviour of 'hidden population' like TGs is very important from a public health purview as their transgression from normative gender roles subjects them to societal stigma and discrimination (Logie, 2012; Melendez et. al., 2006). Such stigma often translates to social and institutional discrimination of TGs on the basis of expression of identity in day-to-day socio-economic spheres, exposing them to violence, mental trauma and other health related risks like substance abuse which have serious health implications for them. (Chakrapani et al.,2011; Horvath et al.,2014; Hughes & Eliason, 2002; Melendez et al.,2006; Niang et al., 2003).

Fighting for an identity translates not only to legal recognition for TGs, but also their acceptance in society and freedom to access basic services like employment, housing, water and sanitation, education and access to government allocated facilities including healthcare without discrimination. Although, there have been attempts to provide legal recognition to them in India by allowing them to participate in elections[1], according them a separate gender status in passport and other identification documents like Unique Identification (Aadhar) Cards as well as the Supreme Court judgement recognising the constitutional rights of TGs in 2015, these have not reduced the discrimination they face in daily life (Agoramoorthy & Hsu, 2014; Chakrapani et al., 2011; Hernandez, 2006; Kalra,2012). Even state level welfare initiatives that attempt to enforce the constitutional rights of TGs, especially in Tamil Nadu, Andhra Pradesh, Maharashtra and recently Kerala[2] have a long way to go to ensure that social justice is achieved for TG.

The Report of the Commission on Social Determinants of Health (2008) has recognised that "social justice is a matter of life and death". It affects the way people live, their consequent chance of illness and their risk of premature death. This paradigm of thought indicates that structural inequities experienced in daily life expose TGs to a disproportionate burden of illness. Research has showed how social stigma and economic marginalisation of TGs force them to participate in commercial sex work (CSW), mental and physical trauma expose them to high rates of substance abuse, and need for acceptance from sexual partners and sexual violence leads to risky sexual behaviour all of which increase their vulnerability to STD and HIV (Agoramoorthy & Hsu., 2014; Chakrapani et al., 2011; Hernandez, 2006; Melendez et. al., 2007; Ramanathan et al., 2014). While research on STD and HIV has helped stem the incidence of these diseases (Ramanathan et al., 2014), the singular focus on sexuality has overshadowed the general health status of TGs. Studies focusing on 'health conditions' of TGs outside the paradigm of sexuality and exploring health seeking behaviour for diseases other than HIV/AIDs are scarce. Keeping this in mind, this study attempts to understand the health status and treatment seeking behaviour including expenditure on health among TG in an urban slum in Mumbai.

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[1]The Election Commission included a category called E3 (eunuch), allowing TGs to participate in elections since 1994.

[2]Tamil Nadu's Transgender Welfare Board provides identification cards to TGs, recognising them as a separate gender category and ensures employment, housing and other social security measures like special ration cards, and enrolment in educational institutions, free sex reassignment surgeries and government health facilities. Other state governments like Andhra Pradesh, Karnataka and Maharashtra are also setting up welfare schemes and recognising TGs as minority groups with special needs (UNDP 2012). Recently the State Policy for Transgenders in Kerala 2015, was announced that recognizes TGs' constitutional rights (State Policy for Transgenders in Kerala 2015)

II. Methods

The study was carried out in an urban slum in Mumbai using mixed method research. The area consisted of migrants dominated by the Muslim community besides the TG population. As per records of the community based organisation (CBO) working in the area, around 1000 TGs reside in the area though such records might not be accurate due to migratory nature of the communities residing in the slum.

Quantitative data for the study was collected from 110 TGs who were selected through snowball sampling. Members of the CBO who belonged to the TG community helped the first author initiate contact with a group of TGs, who in turn assisted in contacting other TGs. All TGs who agreed to participate were included in the study. A cross-sectional descriptive study with a semi-structured interview schedule (pilot tested) using face-to-face interviews was conducted. Information was obtained on diet, lifestyle, substance abuse, health problems faced and health services utilised, direct and indirect expenditure on illness, mode of payment and savings for health including a section on demographic and socio-economic characteristics. All health problems mentioned in the study were 'self-reported'. Emphasis was given on health problems other than HIV status and STD. Hence, information about HIV and STD was recorded only when the respondents disclosed such details openly during the interview. Verbal informed consent was taken from each respondent who participated in the study and strict confidentiality of their identification was maintained throughout the study.

In addition to the quantitative data, five in-depth interviews (IDIs) were also conducted with CBO members as they acted as key informants providing knowledge of the community. The IDIs captured information regarding community life, daily work, dietary habits and reasons for substance abuse among transgender individuals along with their attitude to health and perception of health services. Data for the study was collected between July and August 2014.Quantitative data analysis for the study was done using SPSS version 20.0. Transcripts of the qualitative interviews were reviewed to explore corroborating evidence to elucidate the descriptive results presented in the paper.

III. Results

Socio-economic and demographic characteristics

Table 1 provides information on socio-economic and demographic characteristics of TGs. The mean age of the sample was 35 years. About 50 per cent of the TGs had a community status of '*Chela*' (Disciple), little less than one third were '*Guru*' (Teacher) and 21.8 per cent were older Gurus. IDIs revealed that the Guru-Chela relationship is the most operational relationship within the TG community. Most of the TGs in the area live away from their natal homes and families and the Guru-Chela relationships form the basis of identification of individuals and their status within the community. The *Chelas* are new members of the community who are initiated into the community by their Gurus. In the Guru-Chela relationship, seniority is established not through age but by when a member joined and settled in the community. Hence, a TG Guru can have older *Chelas* who have joined the community later. A Guru's Guru, i.e. elder Gurus are addressed as '*Nani*' (maternal grandparental name). Thus, the TGs in this manner create a 'fictive kin'[3] group within the community. This kin group operates like a traditional family, with strict norms of conduct and manner of greeting, guiding the hierarchical relationship between the Guru and the Chela.

The relationship status of TG showed that one fourth of the respondents had a regular partner. Around one third of the respondents belonged to Other Backward Castes (OBCs) and General Category each, while 14.5 per cent belong to 'others', namely, Scheduled Castes (SCs) and Scheduled Tribes (STs). Almost half the respondents were Hindus, more than one third Muslims and the rest Christians. IDIs revealed that some TGs had converted to Christianity due to welfare

[3] Fictive Kinship involves the adoption of non-relatives into kin-like relations (Ibsen & Klobus, 1972).

activities run by a local church around this locality. One third of the respondents had no formal education and 16.4 per cent had more than 10 years of schooling with mean years of schooling being six. Almost all respondents were working and the mean monthly income was Rs. 12,985.

TGs were engaged mostly in occupations like begging (42.2 per cent), CSW (41.3 per cent) and ceremonial collections by dancing and singing on auspicious occasions like marriages or childbirth (19.3 per cent) (see Figure 1). IDIs revealed that these are 'traditional' occupations of the TG community. Majority of the TGs engage in both begging and CSW due to the erratic nature of income from these occupations. Older TGs mainly attend ceremonies. Educated TGs initially worked in regular offices. However, the stigma faced at work forced them to quit their workplace and shift to traditional occupations of TG members. Some of the educated TGs work in the CBO which is run by TG members. It offers an alternate occupation for some TGs who work there as community level workers running welfare programmes on health and empowerment for the TGs through local non-governmental organisations. The CBO also acts as a support and advocacy group working with local law authorities for protection of TGs.

Figure 2 provides information on the lack of social security measures available for the TGs. A significant proportion of them did not have a bank account (70.0 per cent), more than half had no Aadhar card and 67.3 per cent had no Voter Identity card. However, 63.6 per cent of them had a PAN card.

Migration, living situation and social network

Information on migration, living situation and social network of TGs is provided in Table 2. Almost all the respondents were migrants, with an average of 15 years in Mumbai. A little less than 60 per cent of them were supported by TG friends or acquaintances to migrate. Almost one fourth of them had migrated alone and 16.2 per cent with their Guru. TGs lived either in groups of two to four persons (39.1 per cent) or more than four persons (28.2 per cent) with few of them living alone (14.5 per cent) or with one person (18.2 per cent). Around one third of TGs resided either with their '*Guru bhai/behen*' (other disciples of their Guru), one fifth with their Guru and 13.6 per cent with their own Chelas. Majority (80.0 per cent) of them have connection with their natal family. Among those who visit their natal homes, 69.3 per cent visit once in a year. A little less than half of the respondents also send money home (Table not provided). In case of any personal emergency, however TGs reported that their Guru (48.2 per cent) or Guru bhai/behen (35.5 percent) become their source of immediate assistance.

IDIs revealed that the Guru serves as the initial support system for all new Chelas under their care. They provide shelter, food, teach them about the conduct in the community and how to earn a living. They also provide their *Chelas* monetary assistance when needed, i.e. during visits to their native place, medical emergency, etc. However, this hierarchical structure can get oppressive as well. The traditional system requires the *Chelas* to handover all or most of their earnings to their Guru. This often leads to tension between the Guru and Chela as illustrated in the quote below:

> "*The culture among Hijras is very strong, so if a Guru takes you under her wing then you have to do as she says. It was very rigid earlier, when I had come, now things have changed a lot. People stay away from their gurus in separate rooms but when we had come, we had to stay together with the guru and follow her orders. So soon after I came, I was put to work, people mostly went for sex work and I was also told to do the same. We had to give all our earnings to the Guru, which was something I did not like*" (TG Guru, 33 years).

In the present study, only 27 respondents reported that they gave money to their Gurus, of which 63 per cent stated that they gave more than Rs. 1,000 monthly. Rest were not very forthcoming with information.

Diet patterns and lifestyle

Information on lifestyle and diet pattern of respondents was obtained as they are important indicators of health and well-being (Table not provided). More than half of the TGs work on an average of eight hours or more and 14 per cent work up to nine hours and 12.1 per cent work up to 12 hours daily indicating long working hours. Approximately, three-fourths of them take three meals and the remaining have two meals in a day. Most of the TGs are non-vegetarians with one fifth of them consuming mostly red meat (mutton) at least once in a week. Qualitative information revealed that TGs prefer to consume spicy and oily food as illustrated below.

> "*Where we come from, we do not like bland food. We like spicy food, so we put a lot of masala and chillies in our food*" (TG Guru, 33 years).

> "*We can't use less oil. We buy one kg oil every two weeks for five people*" (TG Guru, 35 years).

Home cooked food is often considered healthy as compared with food from restaurants or outside which is often high on salt, sugar, oil, etc. In order to understand the practice of consuming home cooked food among TGs, information on consumption of outside food, type of food eaten outside and how frequently outside food is consumed were obtained from the respondents. Daily consumption of outside food was reported by a majority (81.8 per cent) of the respondents. The type of food eaten outside consisted mainly of fried snacks in comparison with regular meals like rice and vegetables or curry. Around 40 per cent of the respondents reported weekly consumption (once or twice in a week) of fried food (40.0 per cent) and carbonated drinks (40.9 per cent). More than half the respondents also engaged in daily physical activity, namely, walking. Among those who reported walking, 57.9 per cent stated that they spent on an average five hours or more on such activity.

Consumption of alcohol and tobacco and knowledge of their impact on health

Information on consumption of alcohol and tobacco and knowledge about its impact on health was obtained as these substances cause serious health problems. Table 3 shows that more than half of the respondents consume alcohol. Among those who consume it, more than one third consume daily while 37.9 per cent consume it weekly. The proportion of respondents who consume tobacco is 60.9 per cent. Among them a majority (85.1 per cent) reported chewing tobacco. Daily consumption of tobacco was reported by a majority of the respondents (88.0 per cent) of which 40.3 per cent also consume it multiple times daily.

The Table 3 also shows that 66.4 per cent of the respondents knew about the health problems caused by alcohol. Among them, a majority reported liver problem as the main disease caused by consumption of alcohol. A majority of them (88.2 per cent) were also aware of health problems caused by tobacco consumption and among those knew it, almost all reported cancer as the main disease caused.

Qualitative findings suggest that knowledge and awareness do not make an impact the consumption of alcohol and tobacco among TGs. They think that these substances play an important role in making their life more manageable as illustrated by the following quotations:

> *"In our community, people are always much tensed, they have tension about their home, non-acceptance of our community in society and the harassment we face, and tension from partners. Alcohol and tobacco help us overcome these tensions. People know (that) they are not good habits but cannot avoid them once they are addicted. There is a resistance that you will see… because, there is less hope in this community, they feel life has not been good to them, so they don't value life, don't think anything will improve their life."* (TG Guru, 33 years, current non-consumer).

> *"I know that tobacco causes cancer. However, we have to die someday or the other ('hamein marna to hai kabhi na kabhi'). Like you need your glasses to see better, tobacco helps me live better."* (TG, Nani Guru, 48 years, currently consumes tobacco).

Another aspect highlighted by the findings is the lack of control TGs have over their consumption behaviour as illustrated below:

> *"It (alcohol) is not good at all but clients drink and force us to drink so now am used to it. I don't drink everyday but very often. If clients want you to drink you can't say no."* (TG, Guru, 35 years, currently consumes both tobacco and alcohol).

Information on reported illness, treatment seeking and expenditure on health

Information was obtained on health problems faced by TGs. Both common illness and chronic illness were recorded to understand the burden of disease in the community (see Table 4). To avoid recall bias, information for common illness suffered in last six months and chronic illness suffered in the last one year was collected.

Information on common illness

In the past six months, around 61 per cent respondents had suffered from common illnesses. A significantly large proportion of the respondents suffered from cold and fever (68.7 per cent). One tenth of the respondents suffered from water borne diseases like diarrhoea, typhoid and jaundice and the rest from body ache, skin allergies and other diseases like malaria, gastric problems and weakness. The average duration of common illness was seven days. Regarding treatment seeking behaviour, 41.8 per cent of the respondents took medicine from the pharmacy. Little more than one fourth consulted traditional healers and the same proportion of TGs also went to private doctors. Qualitative information revealed that the treatment seeking behaviour of TGs can be explained by their lack of faith in doctors and the familiarity with local chemists as illustrated in this quote:

> *"If I go to the doctors for any consultation, they suggest take saline drip ('paani chadhao'). This is costly, and costs around Rs. 1,200. So I don't consult doctor unless it is very urgent. Even my Chelas can go to the chemist and take medicines as they know us. Why do we need to go to the doctor for small problems ('halke phulke problem ke liye doctor ke paas kya jana')"?* (TG, Older Guru, Age 48 years).

The mean loss of work days for common illness was three. The mean direct cost of common illness was Rs. 653 while the mean indirect cost (calculated on the basis of loss of wages) incurred was higher at Rs. 1,467. A majority of the TGs (83.3 per cent) had paid from their own pocket for their treatment.

Information on Chronic Illness

Table 5 shows that 40.9 per cent respondents reportedly suffer from chronic illness in the last one year. Chronic illness was further classified into communicable diseases and non-communicable diseases (NCD) using World Bank's classification in global burden of disease (Lopez et. al., 2006). Among those suffering from chronic illnesses, little more than one fifth reported suffering from communicable diseases like AIDS, Tuberculosis and Haemorrhoids. A significant proportion, however, suffered from non-communicable diseases (66.7 per cent). Among those who reportedly suffer from NCDs, cases of diabetes were the highest (40.0 per cent), followed by hypertension (11.1 per cent) along with other diseases, namely, musculoskeletal disorders like arthritis and spondylitis. It is important to point out here that the overall burden of disease might be under represented as information on HIV status was recorded only for TGs who consented to disclose the same.

The average duration of chronic illness suffered was three and a half years and more than half of the respondents suffered for a year or more. Three-fourths of the respondents had taken treatment from private doctors or hospital, 15.9 per cent from traditional healers and few (4.5 per cent each) took medicines from pharmacy or visited a public hospital. There were 11.8 per cent cases of hospitalization for chronic illness and almost all the patients went to private hospitals. IDIs revealed that trust and attitude of the practitioners was a driving factor for the choice of health facility. TGs preferred to visit private doctors who accepted them and understood their problems. The following quotation illustrates this:

> *"Recently, I was admitted to the hospital with complications because my white blood cell count had become very low. I had to spend around Rs. 10,000 in the hospital where I was admitted. It is nearby, in our locality only, XXX (name not revealed here) hospital, we go there. We know the doctors there. We don't have to stand in line also. In other places, doctors don't give us attention and we feel embarrassed talking to them".* (TG Guru, 33 years).

The mean loss of work days for chronic illness was three. The mean direct cost of treatment was Rs. 9,379. Indirect cost was incurred by 40 per cent of the respondents and the mean cost incurred was Rs. 4,113. A significant proportion of the TGs (69 per cent) paid for their own treatment. Guru or Chela' also paid for treatment for 14.3 per cent TGs and 9.5 per cent TGs took loans on interest to meet the expenses of treatment.

Information on health insurance and savings for health

Information about savings for health and insurance was also obtained as it explains actionable attitude towards health. Table 3 provides information on savings for health. A majority of the respondents (88.2 per cent) had not saved for any health emergency. More than half of those who had not saved stated that they had never thought about saving for health care. Knowledge of health insurance in general and government health insurance in particular was also low among a majority of the respondents.

III. Discussion and conclusion

The focus on TGs in India has been reinstated with the acceptance of the Rights of Transgender Persons Bill, 2014 by the Rajya Sabha. Though pending approval in the Lok Sabha, it aims to provide a national policy for development of TGs (Gandhi &Ramachandran, 2015). In addition, the recently announced transgender policy by the Department of Social Justice, Government of Kerala, also brings to the forefront the need to recognise TGs' rights to identity, freedom of movement and access to socio-economic opportunities (State Policy for Transgenders in Kerala, 2015).

Such policies are required to focus on the wider context of marginalisation of TGs and broaden the horizon on their socio-economic and especially, health care needs. Due to their identification as high risk groups in the HIV/AIDS epidemic and constant focus on their sexuality, they face stigma even when seeking healthcare services as health practitioners view their problems only from a narrow focus based on their sexual practices. Thus, the focus on health problems, health needs and healthcare access of TGs is currently limited to HIV/AIDS and STD services, neglecting the broad area of general health problems caused by their traumatised life situations.

The current cross-sectional descriptive study conducted among TGs living in a slum in Mumbai tries to fill this lacuna by looking at their health problems and health seeking behaviour. The study used a mixed method approach consisting of a survey of 110 TGs and IDIs with five key informants. The findings of the study reveal how marginalisation and victimization of TGs in socio-economic spheres restrict them to traditional occupational choices, unhealthy dietary practices and substance abuse, thereby impacting their health. The treatment seeking behaviour indicated a

mistrust in doctors, leading to treatment by them only in case of aggravated conditions, which inflates the cost of treatment seeking and increases the burden of disease.

A majority of TGs were migrants to Mumbai. TGs create a fictional kinship network operationalised by a hierarchical relationship of Guru (earlier entrants to the TG community who initiates new entrants under the tutelage) and Chela (new entrants who become disciples of some Guru). This relationship becomes a source of link, assistance and comfort for TGs. Testa and Rankin (2014) have highlighted that a positive association of TGs with people of their community helps them overcome discrimination. However, qualitative findings of the current study also highlight the oppressive role of the hierarchical structure, where the Chelas have to hand over their earnings to the Guru and abide by his rules, indicating that TGs may encounter oppression not only outside but within their community. Lack of stable relationships with partners as reported in the findings also creates a feeling of isolation. A significant proportion of the TGs had connection with their natal families indicating a possible change in their acceptance by their families, which is in contrast to other studies documenting strained or non-existent family ties among TGs. (Agoramoorthy & Hsu, 2014; Chakrapani et al., 2011; Khan et al., 2009; Melendez et al., 2006).

The socio-economic and demographic information indicates that more than half of the TG respondents had attended some school and a few had above 10 years of schooling. However, the occupational profile revealed that even those who were educated, follow traditional occupations of begging, sex work and ceremonial functions. The qualitative interviews also reveal that some of the TGs had been employed before but had left their jobs on account of the stigma that they were subjected to. This finding is congruent with earlier studies that show how stigma and discrimination limit the employment options of TGs forcing them to take up traditional occupations to meet basic needs (Burge, 2007; Chakrapani et al., 2011; Kalra, 2012; Khan et al.,2009; Melendez et al., 2006; Melendez & Pinto, 2007; Reisner et al., 2014). The reported income levels from the traditional occupations being low and erratic, TGs take up multiple occupations to meet their needs. Discrimination is evident in the lack of legal identification like absence of voter identity card, Aadhar card or bank account among a significant proportion of TGs. Though PAN cards were reported by around sixty per cent of the TGs, they did not recognise their current identity as transgenders as they had been obtained by them before entering the TG community.

The context of victimisation can also be interpreted with respect to the findings about occupation, diet patterns and substance abuse all of which are linked to the marginalisation faced by TGs. Their dietary and lifestyle patterns indicate the negative impact of unstable sources of income. Long and erratic work timings lead to higher dependence on unhealthy food from outside. Consumption of fried snacks, carbonated drinks and preference for oily, spicy, non-vegetarian meals (often red meat) indicate a high calorie diet which may lead to obesity, diabetes and cardio vascular diseases (Moodie et al., 2013). In addition, more than half of the TGs reported regular consumption of alcohol and tobacco. Knowledge of the harmful effects of these substances did not restrict their consumption as qualitative interviews revealed that these substances alleviate trauma of their discrimination. This finding has been corroborated by other studies on TGs and sexual minorities which document higher rates of substance abuse and its correlation with the alleviation of stigma and discrimination (Chakrapani et al., 2011; Lanfear & Atkins et al., 2013; Horvath et al., 2014; Hughes & Eliason, 2002; Reisner et al., 2014).

Looking into health problems revealed a high burden of disease among TGs often goes unnoticed in the umbrella of HIV. Around sixty per cent of TG population suffered from common illness (in the last six months). Information on seeking healthcare showed that TG preferred to consult a chemist for medication in case of common illness.

Around 40 per cent of the TGs suffered from chronic illnesses (recorded for the last one year). Among them, a little more than one fifth suffered from communicable diseases like AIDS (information on which was taken only from those who disclosed their status at their own), Tuberculosis and Haemorrhoids.

The burden of chronic non-communicable diseases was higher. Around two-fifths of those suffering from non-communicable diseases had diabetes and few persons reported suffering from hypertension. The burden of disease is further exacerbated by interplay of factors like not seeking proper health care, delay in care seeking and cost of healthcare. Consultation with private practitioners was preferred for chronic illnesses. However, treatment is taken only when there is an emergency or aggravation of condition and this is true for both common and chronic diseases. This delay in taking action results not only due to lackadaisical attitude to health of TG but mainly from limited options of healthcare providers who can understand TGs' problems. The study points out their lack of trust on existing practitioners. Other studies have also reported that stigma and attitude of practitioners, staff and even other patients become barriers in health care access for TG population (Goldsen et al., 2014; Melendez et al., 2006; Sanchez et al., 2009; Socías et al., 2014).

Further, the cost of healthcare was also reported as a major barrier to seeking health care which often leads to delays in health care seeking and opting for low cost options like medicines from pharmacists for interim relief. This lowers the direct cost for common illness but increases the cost in the case of chronic illness. The indirect cost of both common and chronic illness (recorded as the cumulative of wages lost on account of illness) was also on the higher side, which indicates that delayed treatment seeking may result in an increase in duration of illness leading to loss of wages. Therefore, the downside of delayed treatment seeking is the heightened burden of disease. A national health, aging and sexuality study undertaken in Washington reports a higher burden of disease both mental and physical among transgender older adults emerging from the victimisation that they face (Goldsen et al., 2014). However, in the present study the burden of illness is found high among relatively younger cohort of TGs (average age of sample being 35 years) which can be an indicator of heightened burden in the future. It also reports that the knowledge and practice of savings for any future health problem is negligible among TGs, leaving them exposed to a high economic burden on account of expenditure on health.

Findings from this study indicate that the marginalisation of TGs in terms of expression of identity or not having access to adequate and stable income sources exposes them to unhealthy conditions. Unhealthy diet and erratic lifestyle along with substance abuse may expose TGs to a high burden of diseases, especially NCDs like diabetes and hypertension which were reported as existing morbidities in this study and have been documented in other studies also to be prevalent among poor and marginalized communities in low and middle income countries (Cesare et al., 2013; Moodie et al., 2013). TGs' lack of savings for health care become crucial as they indicate the possibility of increased economic burden imposed by high cost of illness, both direct and indirect, making it a vicious cycle of illness and economic burden leading to increased burden of disease.

V. Limitations of the Study

The current study describes the health problems of TGs in an urban slum of Mumbai. However, it has some limitations. First, it is non-representativeness on account of the use of non-random sampling method. Second, it did not record cases of AIDS since the respondents did not consent, leading to underreporting of the burden of disease in the community. Third, it recorded self-reported illness which may lead to over or under reporting. Fourth, it did not focus on areas like hormonal therapy taken by this population and its possible impact on their health.

VI. Policy recommendations

The study raises serious concerns about the burden of disease faced by TGs and its possible exacerbation due to delay in health care seeking, limited trusted providers and high cost of illness. In addition, the findings on socio-economic discrimination, diet and substance abuse become important determinants that may impact the burden of disease.

The study suggests the policy recommendations: First, recognition of the TG community as a minority group in need of intervention is important so that national and state policies can focus on

their development and bringing them in the mainstream. Although certain policy interventions have been initiated in Kerala, Tamil Nadu, Andhra Pradesh and Maharashtra to integrate them, the current study indicates the urgency to recognise the institutional marginalisation and stigma faced by TGs and to design policies that will empower them to access services that are available to other citizens. Such recognition with special focus on legal identification like Aadhar cards, voter identification cards and opportunities for higher education, vocational training as well as opportunities for educated members of the community to participate in mainstream occupations will help combat the discrimination faced.

The second recommendation is to focus on the health problems of TGs beyond the narrow paradigm of STD and HIV/AIDS. Special policy intervention on providing health education pertaining to the importance of health and early treatment seeking is needed with emphasis on the impact of substance abuse, diet and emergent lifestyle diseases like diabetes and hypertension. These efforts, however, need to be preceded by representative surveys on the socio-economic condition and health problems faced by TGs which will have significant implications on the policies and programmes that are initiated.

Within healthcare, focus on sensitisation of health care providers towards the special needs of TGs is important, especially health care providers in and around areas where TGs reside. Transgender friendly health care models initiated within National Health Service (NHS) in United Kingdom (Ahmad et. al.,2013) and the Fenway model of Boston community health centre show how physicians can be trained or specialised to provide tailored services for transgender health (Reisner et. al., 2015). Similar initiatives can ensure that TGs feel safe and free from discrimination in health care settings. The third and final area of intervention would be generating awareness about public health insurance programmes and encouraging TGs to enrol in current public health insurance schemes operational in various Indian states which will raise awareness about the need for saving for health care.

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Table 1: Socio-economic and demographic characteristics of TGs, Mumbai, 2014

Characteristics	Total		%
Age (in completed years)			
Below 30	43		39.1
30-34	21		19.1
35 and above	46		41.8
Mean age		*34.9*	
Current community status			
Chela (Disciple)	54		49.1
Guru (Teacher)	32		29.1
Nani guru (Older guru)	24		21.8
Current relationship status			
No regular partner	82		74.5
Regular partner	28		25.5
Caste			
Other backward caste	41		37.3
General	41		37.3
Others*	16		14.5
Did not know	12		10.9
Religion			
Hindu	55		50.1
Muslim	43		39.1
Christian	12		10.9
Education (in completed years of schooling)			
0	37		33.6
5-Jan	16		14.5
10-Jun	39		35.5
Above 10	18		16.4
Mean		*6*	
Work status			
Non-working	3		2.7
Working	107		97.3
Monthly income (in Rs.)**			
Less than 10000	51		46.8
10000-20000	49		45.0
More than 20000	9		8.3
Mean		*12985.3*	
N	110		100

Notes: * Others includes scheduled caste and scheduled tribes.
** One respondent was dependent on family for expenses.

Figure 1: Current occupation of TG (per cent), Mumbai, 2014

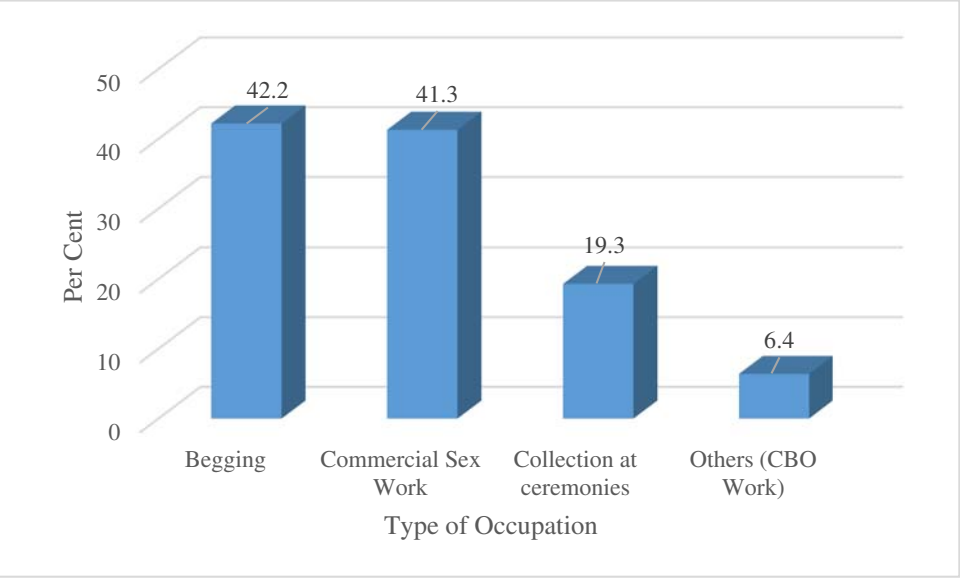

Figure 2: Social security measures available for TGs (per cent), Mumbai, 2014

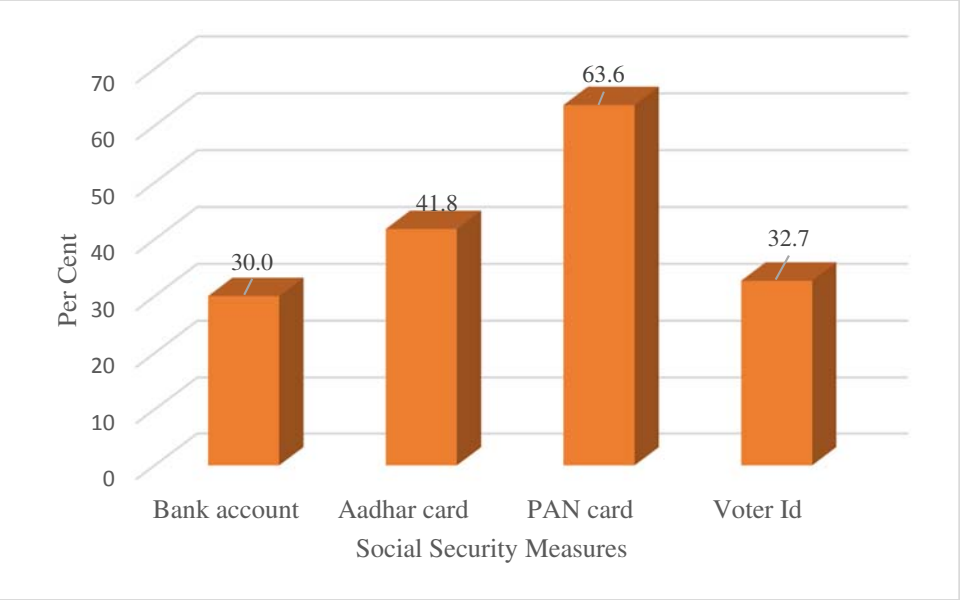

Table 2: Information on migration, living situation and social network of TGs, Mumbai, 2014

Characteristics	Total	%
Information on migration		
Residential status		
Migrant	105	95.5
Resident	5	4.5
Duration of stay in Mumbai (in years)**		
Less than 10	36	35.2
10-19 years	38	37.3
20 or more	28	27.5
Mean	*15.4*	
People who helped to migrate**		
Relatives	2	1.9
TG friends and acquaintances	60	57.1
Guru	17	16.2
Migrated alone	26	24.8
Information on living situation		
Number of people living together		
Alone	16	14.5
One person	20	18.2
2-4 people	43	39.1
More than 4 people	31	28.2
Currently living with		
Guru	25	22.7
Guru bhai/behen	35	31.8
Chelas	15	13.6
Alone	16	14.5
Partner	15	13.6
Family or relatives	4	3.6
Source of assistance in emergency		
Guru	53	48.2
Guru bhai/behen	39	35.5
Chelas	10	9.1
Go back home	5	4.5
Any other (partner)	3	2.7
N	110	100

Notes: *There were three missing responses among migrants who responded to these questions.

Table 3: Information on consumption of alcohol and tobacco and knowledge of diseases caused and savings for health among TGs, Mumbai, 2014

Characteristics	Total	%
Alcohol consumption		
No	52	47.3
Yes	58	52.7
Frequency of consumption*	52	
Daily	20	34.5
Weekly	22	37.9
Occasionally	16	27.6
Tobacco consumption		
No	43	39.1
Yes	67	60.9
Type of tobacco**		
Smoked	7	10.4
Smokeless	57	85.1
Both	3	4.5
Frequency of consumption**		
Daily	59	88
Weekly	2	3
Occasionally	6	9
Knowledge of health problems		
Knowledge of health problems caused by alcohol	73	66.4
Type of health problems caused***		
Liver problems	64	90.1
Cancer	10	14.7
Heart problem	3	4.4
Diabetes	2	2.9
Knowledge of health problems caused by tobacco	91	82.7
Type of health problems caused		
Cancer	90	98.9
Savings and health insurance		
Saved for health emergency	13	11.8
Knowledge of any health insurance	19	17.3
Knowledge of government health insurance	18	16.4
N	**110**	**100**

Notes: *Response taken from those who consume alcohol.
**Response taken from those who consume tobacco.
***Multiple answer type, and so percentage does not add to 100 percent.

Table 4: Information on common illness, treatment seeking and expenditure of TGs, Mumbai, 2014

Information about common illness	Total	%
Common illness suffered in last 6 months		
No	43	39.1
Yes	67	60.9
N	110	100
Type of common illness		
Cold and Fever	46	68.7
Water borne illness*	7	10.3
Headache/back pain/body ache	5	7.5
Skin allergy	4	6.0
Others**	5	7.5
Duration of illness (in days)		
4 or less	39	58.2
5 to 9	19	28.4
10 or more	9	13.4
Mean	*6.7*	
Type of treatment taken		
None/home remedy	2	3.0
Traditional healer	18	26.9
Medicine from pharmacy	28	41.8
Private doctor/ hospital	18	26.9
Public hospital	1	1.5
Loss of work (in days)		
No loss	7	11.9
4 or less	44	74.6
5 or more	8	13.6
Mean	*2.8*	
Expenditure		
Direct cost (in Rs)		
0	1	1.5
Less than 1000	57	85.1
1000 or more	9	13.4
Mean	*653*	
Indirect cost (in Rs)		
0	15	22.4
Less than 1000	17	25.4
1000 or more	35	52.2
Mean	*1467.3*	
Mode of payment* **		
Self	55	83.3
TG guru/chela	5	7.6
Family or partner	3	4.5
Loan on interest	3	4.5
N	67	100

Notes: * Water borne illness were diarrhoea, typhoid and jaundice.
** Other illnesses were malaria, gastric and weakness.
*** Response does not include those who did not take any treatment.

Table 5: Information on chronic illness, treatment seeking and expenditure of TGs, Mumbai, 2014

Information about chronic illness	Total	%
Chronic illness suffered in last one year		
No	65	59.1
Yes	45	40.9
N	110	100
Type of chronic illness		
Communicable diseases*	10	22.2
Non-communicable diseases**	30	66.7
Others***	5	11.1
Duration of illness (in months)		
Less than 12 months	21	46.7
12 months or more	24	53.3
Mean	*42.9*	
Type of treatment taken		
No treatment	1	2.3
Traditional healer	7	15.6
Medicines taken from pharmacy	2	4.4
Private doctor/clinic/hospital	33	73.3
Public hospital	2	4.4
Hospitalisation cases****		
Total cases of hospitalisation	13	11.8
Hospital type visited		
Public hospital	1	7.7
Private hospital	12	92.3
Duration of stay at hospital (in days)		
3 or less	7	53.8
4 or more	6	46.2
Loss of work (in days)		
No loss	27	60.0
Below 4	7	15.6
4 or more	11	24.4
Mean	*3.4*	
Direct cost (in Rs)		
0	3	6.7
Below 2000	23	51.1
2000 and above	19	42.2
Mean Cost	*9379*	
Indirect Cost (in Rs)		
0	27	60.0
Below 2000	7	15.6
2000 and above	11	24.4
Mean Cost	*4113.3*	
Mode of payment		
Self	29	69.0
Insurance	1	2.4
TG guru/chela	6	14.3
Family/partner	2	4.8
Loan on interest	4	9.5
N	45	100

Notes: *Communicable diseases were AIDS, TB and Haemorrhoids.
**Non-communicable diseases were arthritis, spondylitis, diabetes, hypertension and anaemia.
***Other illness were UTI, gastric problems, epilepsy and stones in gall bladder.
****Response was taken from those hospitalised for chronic illness.